Understanding Stigmatization, Psychological Burden and Quality of Life among Patients of Epilepsy

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Abstract
The current study was conducted to investigate the impact of perceived stigma and psychological burden on the quality of life among the patients of epilepsy. Sample of 560 (male=221, female=339 epileptic patients were selected through purposive sampling technique from Nishtar Hospital Multan and Combined Military Hospital Multan. Findings showed that perception of stigma, depression, anxiety and stress have a significant positive correlation. Stigma is a significant positive predictor of psychological burden. Results also indicate that stigma and psychological burden are significant negative predictors of quality of life. Significant differences were found in the demographic variable gender on stigmatization, psychological burden and quality of life. Stigma, depression, anxiety and stress are significantly higher in female epileptic patients as compared to male and has a detrimental effect on the patient's quality of life, recovery, and prognosis. Thus, there is undoubtedly a need to address psychological issues, most notably the stigma associated with illnesses. Psychologists, psychiatrists, other physicians, and care givers of epileptic patients must pay close attention to the stigma in this patient population.
Keywords: Stigmatization, Psychological Burden, Quality of Life, Patients, Epilepsy

1. Introduction

Individuals suffering from psychiatric conditions face enormous challenges in their daily lives. People with severe mental illnesses are more likely to have low self-esteem, internalization of negative beliefs, a low level of hope, difficulties with social relationships, a lower likelihood of adhering to treatment, difficulties at work, unemployment, and all of this is driven by stigma and discrimination, which eventually has a negative impact on recovery. In many ways, they are marginalized and discriminated against and are not given the opportunities that define a good life. Many people with severe mental illnesses struggle to meet basic needs such as education, safe and stable housing, good jobs, and decent healthcare (Boling, et al., 2018).

In addition to mental illness, stigmas surround neurological disorders such as epilepsy. Despite medical advances, there are still stigmas and misunderstandings about epilepsy. The stigma associated with epilepsy includes both the stigma experienced by epilepsy patients and the community's attitudes and beliefs about them. Patients with epilepsy may feel ashamed and embarrassed if they have a seizure in public due to symptoms such as limb shaking, staring spells, chewing, and urinary/bowel incontinence (Boling, et al., 2018). Unfortunately, they face prejudice and stigma from others as well because they are perceived as insane, possessed by evil spirits, and having weak minds. The word "epilepsy" conjures up images of a person having fits (seizures) at any time, which has a negative impact on their social relations and quality of life. People with epilepsy (PWE) who live in underprivileged areas, unfortunately, do not receive appropriate care, which often results in their illness remaining untreated, affecting both their physical and psychological health (Lee et al., 2016).

Perceived stigma is a risk factor for the development of psychiatric conditions such as anxiety and depression in people with epilepsy. According to a recent study, patients with epilepsy perceived 25% of high stigma 55.0% anxiety, and 47.5% severe depression (Ranjan et al., 2022). Epilepsy-related stigma is not only prevalent in developing European and Middle Eastern countries but also in developed countries (de Souza et al., 2022). Even though physicians are meticulous in diagnosing and treating epilepsy, they invariably neglect to address the associated stigma, which can lead to psychological problems such as depression, anxiety, and suicidality (Holmes et al., 2019). Psychological morbidity is significantly more prevalent in people with epilepsy than those without the condition (Doganavsargil-Baysal et al., 2017). The psychological morbidity includes increased levels of depression and anxiety, social isolation, and withdrawal (Wang et al., 2018).

People having epilepsy face several social problems and these social aspects have more negative effects as compared to the disease itself. Studies revealed that individuals with epilepsy are likely to have worse self-worth and have a high rank of depression and anxiety than individuals without epilepsy (Yıldırım et al., 2018). Individuals experiencing epilepsy suffer from depression at two to three times the rate of the general population (Vaingankar et al., 2020), and they are more likely to suffer from depression than people with other chronic conditions (Walsh et al., 2018). Studies have found that there is a substantial connection between depression, anxiety disorders, and epilepsy. Approximately

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one in five of all adults who experience epilepsy suffer generalized anxiety disorder (GAD), and at times epileptic children show symptoms of depression and anxiety (Luna et al., 2017).

Quality of life also has an impact on the people living with epilepsy, and empirical evidence revealed that the individuals with epilepsy as a cluster have poor QOL as compared to those without epilepsy (Yeni et al., 2018). For example, Yeni and his colleagues (2018) conducted a study in which they compared health-related QOL in adults with and without seizures in a large sample and reported that patients with seizures reported high levels of psychological distress, sleep problem, and pain as compared to the individuals without seizures and were also more likely to develop serious mental illnesses.

Researchers have made significant progress in gaining a better understanding of the neurobiological basis, diagnosis, and treatment of epilepsy. However, psychological problems persist and have a detrimental effect on recovery from this condition and prognosis. Thus, there is certainly a need to resolve psychological issues, particularly the stigma associated with illnesses. As most of the previously done studies have been conducted by physicians and neurologists, so they lack prevalence data, frequency, mode of onset, and causes of epilepsy (Asghar, et al., 2021). Psychologists and psychiatrists need to focus on the psychological as well as social issues of people with epilepsy. According to World Health Organization (WHO), people with epilepsy can live a normal life medically, but unfortunately, this stigma related to the disease affects their lives; even having no medical difficulties makes their life harder. According to WHO around 50 million people worldwide suffering from epilepsy, in developing countries, almost 80% of people live with epilepsy. There is 3 times more premature death for normal people with risk of epilepsy. 3 quarters of people with epilepsy living in developing countries do not get the treatment they need. The global prevalence of epilepsy is generally taken as between 5 and 10 cases per 1000 persons by WHO in 2019. Few studies have come from developing countries (Malik et al., 2022). Few epidemiological studies of epilepsy are available from Pakistan (Yap et al., 2017). Epilepsy has not been thoroughly investigated in Pakistan and epilepsy has a huge prevalence rate of 9.98% per 1,000 populations, in Pakistan that is twice as common in rural areas mostly among younger population less 30 years of age (Bilal & Ansari, 2021). It has been estimated that its spread rate is greater in countryside areas than urban areas. About 25% cases are genetic and different types of seizure are present in developing countries (Bhesania et al., 2014). So, Family history is an important risk factor for this disorder. This prevalence of epilepsy and their psychosocial issues were also found to be dependent upon the country's health care system, socioeconomic status and community response toward patients. Especially in collectivist country like Pakistan it is very much evident that psychological health of epileptic patients and even their caregivers have been strongly associated with the attitudes and perceptions (stigma and discrimination) of their community as well which are more harmful than the disease itself (Ullah et al., 2018). Epilepsy patients' demographics have also been studied in Pakistan, (Trinka et al., 2019) but very few studies are conducted on the psycho-social factors affecting the patients with epilepsy in Asian countries (Malik et al., 2022).

There is scarcity of the studies in the Pakistan especially in Multan in the domain of epilepsy with exploring stigmatization, psychological burden and quality of life. The purpose of the study was to investigate the predictors of quality of life among epileptic patients.
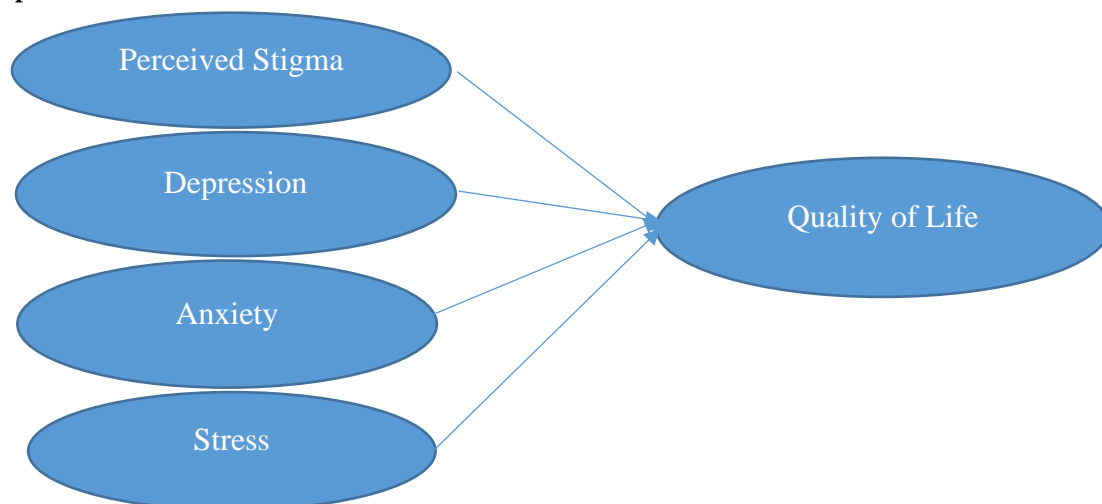
2. Conceptual Framework

Figure 1: Conceptual Framework

This conceptual framework describes perceived stigma, depression, anxiety and stress as the predictors of the quality of life among the patients of Epilepsy.

2.1. Objectives of the Study
➢ To investigate the impact of perceived stigma, depression, anxiety and stress on quality of life among patients of epilepsy
➢ To compare the level of perceived stigma, depression, anxiety, stress and quality of life between male and female

3. Methodology

3.1. Participants

In the present study, a co-relational research method was used, and a sample of 560 individuals with epilepsy was collected by using a purposive sampling technique. Both genders were included in the sample, i.e., 221 males and 339 females.

3.2. Instruments

➢ Stigma Scale (Lovibond & Lovibond, 1995)
➢ Depression Anxiety Stress Scale (Cramer et al., 1998)
➢ Quality of life in Epilepsy-10 (Malik et al., 2022)

3.2.1. Stigma Scale (Lovibond & Lovibond, 1995)

The study use 28 items total scores on stigma scale to measure the constructs of stigma whereas one of its sub-scale namely discrimination was used to measure the variable of discrimination in present study. The stigma scale is originally comprised of 3 sub-scales (viz. discrimination, disclosure, and positive aspects), of which nine items were reversely coded. It is a self-report measure with five-point Likert-type response format. The Cronbach's alpha for the stigma scale was 0.87, and the subscale discrimination, disclosure, and positive aspects were found to have 0.87, 0.85, and 0.64, respectively (Lovibond & Lovibond, 1995).

3.2.2. Depression Anxiety Stress Scale (Cramer et al., 1998)

Depression Anxiety Stress Scale (Cramer et al., 1998) was used to measure the psychological problems. Depression anxiety stress scale consists of 21 items and has three subscales, depression (item no. 3, 5, 10, 13, 16, 17, and 21), anxiety (item no. 2, 4, 7, 9, 15, 19, and 20) and stress (item no. 1, 6, 8, 11, 12, 14, and 18). In the present study, Depression and Anxiety subscale was used.

3.2.3. Quality of life in Epilepsy-10 (Malik et al., 2022)

Quality of life in epilepsy scale consists of 10 items and has six subscales, i.e., emotional well-being (1, 2), social functioning (3), overall quality of life (4), cognitive functioning (5, 9), seizure worry (6–8) and medication effects (10).

3.3. Procedure

Participants were only recruited in the present study if they fulfilled the criteria. According to the criteria, individuals who were diagnosed with epilepsy at least a year ago were eligible to participate. After the recruitment of participants, their consent to take part in the present study was obtained. The authorities of the institutes were also approached, and their policies were taken into consideration. The researcher personally administered the questionnaires to the participants to avoid any errors. Furthermore, the obtained data were analyzed using SPSS version 22, and to test the hypothesis of the present study; regression analysis and t-test for independent samples design were applied.

4. Results

Table 1: Correlation matrix among Perceived Stigma, Depression, Anxiety, Stress and Quality of Life

Variable	Mean	Std. Deviation	S	D	A	S	QA
Perceived Stigma	36.3630	12.90312	1	.753**	.691**	.751**	-.701**
Depression	60.7461	19.07654		1	.856**	.7.48**	-.597**
Anxiety	19.7215	32.79322			1	.692**	-.865**
Stress	29.9032	17.56532				1	-.698**
Quality of Life	24.0961	45.67901					1

**.Correlation is significant at the 0.01 level (two tailed)

Table: 2 Impact of Perceived Stigma, Depression, Anxiety and Stress on Quality of Life

Model	Unstandardized Coefficient B	Std. Error	Standardized Coefficients Beta	t	p-value
(Constant)	88.899	6.986		15.151	.000
PS	-.744	.493	-.701**	-12.986	.000
D	-.589	.599	-.597**	-17.901	.000
A	-.691	.398	-.865**	-16.765	.000
S	-.761	.491	-.698**	-19.892	.000

R^2 = .698, Adjusted R^2 =.699.

Table 3: Comparison of Perceived Stigma, Depression, Anxiety, Stress and Quality of life with respect of Gender

Variables	Gender	N	Mean	Std. Deviation	df	t-test	p-value
Perceived Stigma	Male	321	23.9742	42.64756	558	16.4756	.000
	Female	239	41.7546	47.75341			
Depression	Male	321	29.3542	36.63473	558	13.9532	.000
	Female	239	31.6765	45.12321			
Anxiety	Male	321	26.6574	39.32431	558	11.5764	.000
	Female	239	36.7951	41.56732			
Stress	Male	321	24.7112	37.74634	558	17.6453	.000
	Female	239	33.6723	46.78632			
Quality of life	Male	321	19.7212	51.65736	588	-15.0463	.000
	Female	239	13.2391	49.26201			

5. Discussion

According to the WHO reports (2022), 49 per 100,000 people are diagnosed with epilepsy in high-income countries each year; however, this figure is quite high in low-income countries, i.e., 139 per 100,000 each year (Benson et al., 2016). Individuals with epilepsy face a variety of psychosocial issues in addition to physical hazards. Labeling someone with epilepsy itself has its toll, and it comes with a stigma attached to it (Mendes et al., 2017). Thus, the current study is an attempt to shed light on some of the psychosocial difficulties that people with epilepsy face in Pakistan. The findings of this study were similar to previous studies in that stigma perception has a significant positive correlation with depression, anxiety and stress. The previous studies showed similar results, e.g., Yildirim et al. (2018) also worked on epilepsy patients of age ranging from 19 to 65 and found a significant positive correlation ($r = 0.30$, $p < 0.001$) between stigma and psychological burden.

Souza et al. (2018) studied sixty epilepsy outpatients of a hospital in Campinas, Brazil, with ages ranging from 20 to 45 years and found 26.6 percent perception of stigma and 31.6 percent depression in the epilepsy patients. Another research study also found similar results, i.e., Walsh et al. (2018) studied the perceived psychosocial consequences of epilepsy and found that the stigma perceptions are related to increased psychosocial health consequences such as depression and anxiety in epileptic patients. Wang and his colleagues (2018) conducted a study on 300 patients, both male and female. The research found that epilepsy stigma had a significant impact on depression and quality of life. In addition, Blaszczyk et al. (2016) investigated the role of social support in epilepsy self-help groups. Researchers measured the level of stigma, anxiety, and depression in their study, and stigma was found to be significantly correlated with anxiety, stress and depression. Similarly, the current study hypothesized that a significant positive correlation exists between perceived stigma and anxiety, which is consistent with previous studies such as Oluwole, Obadeji, and Dada (2015), which investigated the determinants of anxiety and depression in patients with refractory epilepsy and found 40.63% depression and 71.43% anxiety in them. Depression and anxiety both showed a positive correlation with stigma in their study. Besides that, the research found that 42.9% of epileptic patients with depression felt stigma, while 71.4% of epileptic patients with comorbid anxiety felt stigma.

According to de Souza et al. (2018) people with epilepsy attach a stigma to themselves or their epilepsy, resulting in discrimination, which causes epileptics to be preoccupied with their disease and spend much of their psychological energy on disclosure anxiety vigilance, and a consequent uncertainty of identity. In a study conducted in Brazil, Souza et al. (2018), sought to examine anxiety and depression in patients with epilepsy and their relationships to psychological and neuro-epilepsy variables. They noticed that 33.3% of epilepsy patients suffered from anxiety. Additionally, epilepsy was associated with the disease (63.4%), mental distress (11.6%), feelings of dishonor, fear, agony, low self-esteem (56.6%), and the perception of stigma (26.6 %). Perceived stigma intensifies stressful situations and impairs the patient's ability to cope with them. As a result, many people with epilepsy experience anxiety when interacting with society. The fact that anxiety appears to be strongly correlated with stigma explains why mainstream reports have found elevated anxiety levels among people with epilepsy in varied countries (Hopker et al., 2017).

Present study hypothesized that an inverse relationship between quality of life and perceived stigma exists among epilepsy patients, which was supported by the findings in the present study. Many Asian countries had negative attitudes and stigmas toward persons with epilepsy in employment and marriage (Engidaw et al., 2020). Similarly, Malik et al (2022) studied 64 older adults and found that their health-related quality of life scores was significantly lower. Their research also found a link between high perceived stigma and frequent seizures and poor psychosocial function and quality of life. Other studies' findings mirrored the present study, e.g., In a comparative study,

Vaingankar et al. (2020) found that people with epilepsy have a lower quality of life than the general population and people with migraine. Many other studies found high levels of stigma among epileptics (Tareke et al., 2020).

The current study also sought to investigate the relationship between perceived stigma, depression, anxiety, stress and quality of life. Our research showed statistically significant links between stigma, depression, anxiety, stress and quality of life. Previous literature also supports this notion that epilepsy is also related with a significant level of feeling of stigmatization, psychosocial burden , feeling more socially restricted, lower self-efficacy, and somatic problems ((Tombini et al., 2021). The present study also looked at demographic difference and found significant differences in demographic variable gender. Previous study reveal that quality of life varies significantly by socioeconomic status, indicating that epileptic patients with high socioeconomic status have a higher level of quality of life than the other groups. Though certain psychosocial factors have been found to be linked with higher levels of reported stigma which entails low feelings about life and perceived impact of epilepsy, patient satisfaction, perceived helplessness, depression, anxiety, somatic symptoms and poor quality of life still it was observed that patients with high level of socio economic status enjoyed good quality of life due to ease/access to medical facility and their family awareness and conscious efforts for making their loved ones life better (Tombini et al., 2021).

6. Conclusions and Implication

The present study shows that individuals with epilepsy who confront stigma have high levels of depression, anxiety, and stress resulting in a low quality of life. The study's findings can help us better understand the psycho-social issues that people with epilepsy face. Results of study also supports the need to consider the psycho-social issues primarily besides those related to epilepsy, its medication and use of psychological interventions as an adjunctive treatment for epileptics for enhancing their quality of life at large. The role of health care systems especially the health care providers i.e., clinical psychologists, psychiatrists, general practitioners, and medical specialists who treat epileptic patients is crucial that they must familiarize themselves with the social and cultural aspects of epilepsy, as well as close pay attention to addressing stigma in this patient population. Furthermore, future research in the field must aimed at evaluating and overcoming main factors contributing to the stigmatization process by improving the knowledge on the epilepsy through awareness culture in community and educational interventions.

7. Limitations and Suggestions

Results of present study should be seen cautiously because of certain limitations. Data was collected through self-report measure that may inflate the results, whereas the use of co-relational research method is another caution while considering the findings to generalize. Use of multi-method approach, combination of interview and quantitative data, or to use experimental design with control group is suggested for future research endeavors in the same domain. Finally a larger sample may be effective to examine the smaller effect size as well.

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